



# Consequences of HIV for Children: Avoidable or Inevitable?

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## Consequences of HIV for children: avoidable or inevitable?

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The HIV/AIDS epidemic has many serious consequences for children. These consequences are, however, rarely inevitable. Families can provide a protective barrier that deflects blows, or minimises their impact and a supportive nurturing environment that can help children recover from harm. If strong enough, and with sufficient access to quality services and support from communities, families can reduce the impacts of HIV/AIDS on children to negligible levels in most areas of impact. It is apparent that the impacts felt by children are not simply unfortunate, inevitable consequences of this epidemic. A strong and supported family with good access to quality services can deflect almost all of the impact. It is as a result of an interaction of the context of poverty, which weakens families, and a failure to adequately respond, that impacts are felt by children.

**Keywords:** HIV; children

### Introduction

The Joint Learning Initiative on Children and AIDS is based on the premise that HIV/AIDS has negative implications for children and that actions can reduce these impacts. The first part is easy to accept, and the second is, to an extent, similarly easy to accept. No doubt HIV/AIDS has negative implications and that actions can reduce these, the question is to what extent can they be reduced and by what actions? This paper seeks to speak to this question by discussing what impacts on children are avoidable and which are inevitable.

Families can provide a protective barrier that deflects blows, or minimises their impact and a supportive nurturing environment that can help children recover from harm. If strong enough, and with sufficient access to quality services and support from communities, families can reduce the impacts of HIV/AIDS on children to negligible levels in most areas of impact. While the potential exists for the family to protect children, they often lack material resources, receive limited outside support and have poor access to appropriate, quality services leading to serious consequences for children.

The impacts of HIV/AIDS on children are well documented in this issue and elsewhere (such as Foster & Williamson, 2000; Hunter & Williamson, 2000, 2004; Richter, Manegold, & Pather, 2004; Sherr, 2008; Subbarao & Coury, 2004; USAID, 2004). A detailed description of these impacts will not be repeated; rather what this paper seeks to do is examine the pathways to impact and to question their

inevitability by drawing on insights from previous work. By extracting from existing work, a conceptual framework will be developed. This will be followed by an examination of the pathways to an impact that will be undertaken by drawing on this framework. The examinations will consider two areas of impact.

- Child infection and
- Adult illness and death.

For each of these it is obvious that, if the infections of parents, caregivers and other adults whom children rely on, or interact with, had been prevented there would not be an impact on children. More than this, the paper will argue that even when adult prevention has failed, the impacts on children are, in almost all instances, not inevitable.

### Conceptual framework

The conceptualisation of the problem plays an important role in shaping perceptions of what the required response is. Rather than examining the child in isolation, the framework on which the paper is based considers the child within the family context. It is suggested below that there are six components to family care that are important here. These six interact to determine the extent to which the needs of children are met and can be summarised in Figure 1.

Without intentions to care for the child, no care will be provided. Intentions may be affected by the gender of the child, their age and their relatedness and may thus play a role in shaping discrimination.

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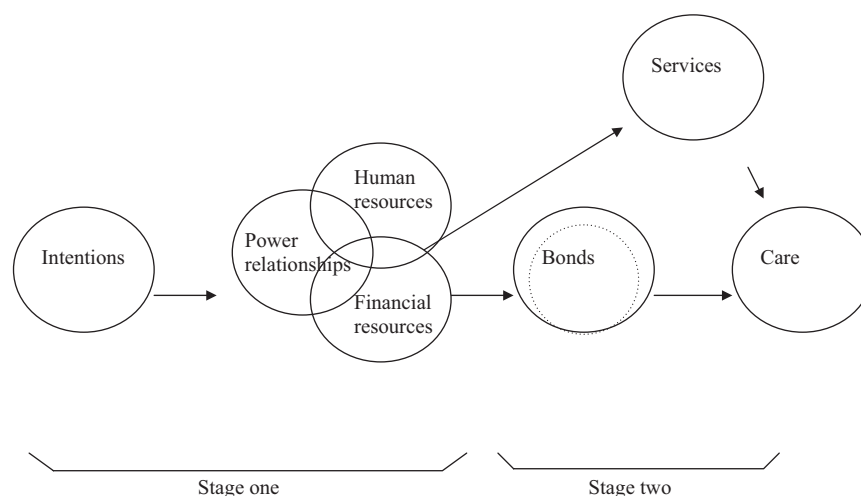


Figure 1. Conceptual framework – production of care.

Indeed intentions may even be negative. For intentions to be translated into care, they require human and financial resources. The extent to which resources in the household can be directed towards care are shaped by the power relations within the family, particularly the power of those with the intention to care.

Allocating human and financial resources can be characterised as determining the level of care provided (stage one). The effectiveness of a given level of care is influenced by the environment in which it is delivered (stage two). The opportunity for the child to form significant and secure bonds, the level of access to services, the quality of these services and access to other forms of social support are all important. Bonds are distinct from intentions in that they require the stable presence of an adult. Resources directed towards the child who does not have this opportunity to form significant and secure bonds will be limited in their impact – more so the younger the child – as they are important in creating the right emotional environment and sense of security necessary for children to thrive. These bonds are an important part of what sets families apart from residential care facilities. Residential facilities may have significant resources but the effectiveness of these resources is reduced by the environment in which care is delivered. When adults develop close bonds with children this may reinforce the intentions to care. The double circle around bonds signifies the diminishing importance of this factor for older children.

Families alone cannot provide for all of children's needs. For example, education, health care, legal protection and social welfare services require outside support and delivery. Access to services is, therefore, important in determining the outcome of a given level of care. Distinct from services is the importance of

links to social support. Social supports can assist in supplementing shortfalls in human and financial resources and linking families to services. While the conceptual framework focuses on the family, it is essential to consider families' links to the community in which they operate, as the ability of the family to function may well be determined to some extent by these links.

### Child HIV infection

There are a number of ways in which children are infected with HIV, one of which is sexual transmission. The question as to what extent this is avoidable is a critical issue, but our lack of knowledge on what is effective makes its inclusion here difficult. The focus of this section, therefore, will only be on vertical transmission.

The child's risk of contracting HIV from their mother is shaped, to a large extent, by the context. The prevalence of HIV shapes the risk of the mother being HIV positive, and poverty and poor maternal health may influence the risk of transmission (Coovadia et al., 2007; Coutoudis, Pillay, Kuhn, & Coovadia, 1999; Creek, 2006; Illiff et al., 2005).

For some time now, approaches to the prevention of vertical transmission have been available which can lower infection rates to below 2%, as opposed to the near 30% without intervention (Gray & McIntyre, 2007; Mofenson, 2004). Such interventions are, however, typically only available to the wealthy.

In most highly affected countries, prevention services have poor coverage and provide a sub-standard intervention (transmission reduced to 15% rather than 2%). While some governments report relatively high rates of cover of these interventions,

the majority either do not report, or report much less than 50% coverage (UNAIDS, 2007).

Recalling the conceptual model, accessing services requires intentions to care and directing of financial and human resources towards accessing services. Taking a mother's intentions towards her unborn child as given for a moment, access to preventative services requires, firstly, that they be available and, secondly, that the mother has access to, and control of, sufficient resources to make use of them. Some families may not have the resources to access services and as a result, even when they are available, they are not used. Avoiding infection, therefore, requires a consideration not only of the supply of services but also of the constraints on demand.

Children infected with HIV face difficulty and often have short lives. In the absence of treatment, the large majority of infected children will die before their fifth birthday (Newell et al., 2004). Paediatric antiretroviral (ARV) treatments are, however, available and can keep children relatively healthy for prolonged periods of time. Unfortunately, availability of this treatment in most high-prevalence countries is poor. Paediatric treatment coverage lags far behind adult treatment coverage rates. It is estimated that only 15% of children who need ARV are currently receiving them, compared to 28% of adults in need of them (WHO, 2007).

The ill health and death of children as a result of being infected with HIV by their parents are perhaps the clearest examples of an avoidable consequence of HIV. The poor response to children in this regard leads to some 420,000 children being infected and 330,000 dying every year (UNAIDS, 2007). Associated with this is the suffering of children and families, the high costs of care and the loss of the potential that was embodied in these children.

### **Adult illness and death**

Adult illness and death within the household or family network can affect children in a number of ways: human and financial resources may become strained and adults with caring intentions may become ill. As a result, the flow of resources to children may be reduced. Moreover, the illness and death of a caregiver may affect outcomes for children as the bonds children have formed with them are strained during illness and broken by their death. The loss of primary caregivers or income earners may have major implications.

The impact on the child is, to a larger extent, determined by who is infected and the levels of human and financial resources prior to the advent of illness and death. If households have sufficient

reserves of financial and human resources they can deflect or absorb much of the impact so as to protect the child. Pre-existing poverty plays a weakening role by diminishing family capacity. The level of impact on the child, resulting from an adult infection, is related to the level of poverty in which the family lives.

Serious illness of any kind has the potential to impact on households. It increases demands on financial and human resources while decreasing the availability of both (Bachmann & Booysen, 2006; UNAIDS, 1999). Unless there is a sufficient excess of these resources, increases in demand will not be met or there will be a need for substitution, involving reductions in the allocation of resources to other expenditures or tasks. As a result of the age distribution of infection, those infected are often those who have the highest levels of human resources and contribute more to financial resources. When more than one such person in the household is infected, the situation becomes even more difficult. Given the sexual nature of transmission, there is a very real possibility of clustering of infections within households or family.

The loss of earnings and productive capacity is linked not only to the loss of capacity of the infected and ill household member; they also require care, which demands the allocation of resources. This exacerbates the impact on children by potentially causing a further fall in the household budget, as other productive members engage in care activities; at the same time the demands on the household budget increase as a result of material care demands. When savings are used to meet expenditures of this type there is the possibility of serious long-term negative implications. It is particularly serious when households are strained to the point that they sell productive assets (Donahue, 2005). Losing productive assets reduces the earning potential of households, leading to the perpetuation of difficulties and limiting the opportunities for recovery.

Even if the household budget remains relatively stable, the increasing costs of care may be met by reallocating money that would have been spent on other goods. In situations where household expenditure was low before the crisis of illness, the impact may well push consumption of basic items to dangerously low levels that can result in both short and long-term health and education impacts for children (Foster & Williamson, 2000; Mutangahura, 2000; Richter et al., 2004; Topouzis, 1994; ). Differential intentions towards children of different sexes, ages, degree of relatedness and parentage may become important when resources are strained, leading to

uneven reallocations (Case, Paxson, & Ableidinger, 2004).

A very direct impact of tighter budgets may involve reduced consumption (Bechu, 1998; Mutangadura, 2000). Households may not be able to maintain expenditures on food and they may favour allocating what food there is to ill household members (Bachmann & Booyesen, 2006). Given the high rates of malnutrition already prevalent in many high-prevalence regions, it is obvious that a further decline will mean consumption, for many households, will be below the necessary level to allow for proper growth and development (Richter et al., 2004). Not only can this impact on the physical development of children, it can also influence their educational attainments.

Children may be withdrawn from school as a result of budget constraints in order to reduce expenditure (Foster & Williamson, 2000). Financial strains may result in reduced spending on education even if children are kept in school. This may involve less spending of text books, stationery and other related items (Bachmann & Booyesen, 2006).

Evidence has been found that some households, while increasing expenditure on health during the period of adult illness, increase it only for HIV-related problems, and that health care expenditure on other members may well fall (Hunter & Williamson, 2000; UNAIDS, 1999). Reduced access to services, resulting in the possibility of reduced immunisation and increased length of illness or untreated illnesses, has obvious detrimental implications for children (Hunter & Williamson, 2004).

At the same time as there are increased financial demands, care demands increase the need for human resources (Bachmann & Booyesen, 2006; UNAIDS, 1999). If families have excess human resources, or are able to call on additional resources or services in times of crisis, they can deflect impacts away from children. If, however, families are faced with tight human resource constraints, the extra demand may well result in reallocations, such as reduced care provision to other household members, reduced production and allocation of tasks to previously uninvolved members, such as children or the elderly. In these circumstances, the quality of care provided to children may well fall. They may be given less time, less supervision and, as a result, less protection; if children are required to take on additional household tasks, they could experience negative impacts on their health and education. In the most extreme, although not uncommon, situations where children take on major roles such as caring for a terminally ill adult, they risk suffering and distress, as well as having to drop out of school and possibly to become HIV-infected (Richter et al., 2004; Sherr, 2008).

The final stages of illness and the eventual death of a household member place yet more demands on household resources associated with care and then meeting funeral costs. The financial and human resource demands are often greatest during this final period of illness and subsequent death (UNAIDS, 1999). If household income, savings or outside support, are insufficient, such crises may push households down to a level from which it is difficult to recover.

Impacts tend to occur because of pressures placed on human and financial resources at the family and household level. There are, however, additional emotional impacts that result from experiencing the illness and death of someone close. On top of this, there is the potential stigma and discrimination that children may experience. Again the family can, to some extent, protect children from long-term harm from these impacts. A supportive and protective home can help children deal with the emotional strain of the illness and death. Suffering and loss are always going to be difficult for children, a protective family in this instance may not be able to negate the impact but the family can certainly help reduce the emotional strain. Protecting children from the impacts of stigma is more difficult and requires actors outside the family, such as teachers and civil society organisations, to play a part. If children do not receive enough protection at this time, there can be long-term psychological consequences.

If the household member lost is a parent, the impact may be very large. The loss of a mother is likely to have the greater impact on children's care. It has been observed, in a variety of contexts, that when a father is lost the children are likely to stay with their mother (see for example Desmond & Desmond, 2006). If, however, the mother dies, many children do not live with their father. It is important to note the context here. Many children across Africa do not live with both of their parents, even if their parents are alive. This is particularly clear with regard to fathers; children and fathers are often separated. In South Africa, this is more often the case for poorer households and is probably related to economic coping mechanisms (Desmond & Desmond, 2006). The tendency of children to stay with their fathers whether their mothers are dead or alive is, however, highly context specific and it is not safe to assume that the Southern African pattern will always be observed (Hosegood, 2008).

The adult loss may well negatively affect the stock of human resources in the household, particularly if the adult was the primary caregiver. If a new caregiver is needed, they may not have the same skills and knowledge as the lost caregiver. The caregiver may



have lower human resources if care responsibilities are extended to older or younger members in the household. Older individuals may not be as physically able to provide care and, given recent increases in illiteracy, they are less likely to be literate, which has implications for children's education (Richter & Desmond, 2008). Younger caregivers may not possess the necessary knowledge or experience.

Following the death of a household member, if the household is no longer able or willing to provide care for the children, they face being moved and being separated from family and community resources. Of course, it is possible that they could be moved to a household with more human and financial resources, strong caring intentions and adequate opportunity to form bonds. The contexts in which the epidemic is most prevalent, however, means that this is not often the case. The context is also not static and as the epidemic progresses the capacity of networks may be drained by continuing demands.

There are only a few countries in highly affected regions where there are social security payments for the support of children. This means that children increase the costs of households without typically increasing the income. If the household is already finding it difficult to meet its members' needs, the absorption of additional members may impact on the welfare of all household members, including children who were previously living there. Faced with financial pressures, households will have to make expenditure decisions that, again, have the potential to negatively impact on the welfare of children in the household. The situation is, however, somewhat different from the pre-death scenario. Firstly, on entering a new household, it may be difficult to form the necessary bonds with the adults in the new household. This may be particularly so when children move into larger households. This possibility is important, as children need to feel secure and supported so that they may recover from the strain of their loss and move. Secondly, there is possibility that the intentions towards the children may not be as strong as they were in their previous home. There is a possibility that the moved children will be discriminated against when scarce resources are allocated.

The above impacts manifest themselves in poor performance and outcomes for children who are moved and, at times, children living in households that take them in. As many of these impacts come about as a result of a lack of financial resources, it has sometimes been difficult to distinguish the poor outcomes for orphans from those of other poor children (Arnab & Serumaga-Zake, 2006; Case et al., 2004). Orphaning, for the reasons discussed, increases the

risk of children being poor, but does not define who is, and is not, poor.

There is also the possibility that children will leave the household in which they were living and not move to another; they may end up living on the street or in residential care. Both of these settings have negative implications for children. The street means less, or no, access to education and health services, as well as no protection. Group residential care may do better in terms of material resources but the difficulty in forming bonds can have long-term developmental implications for children. As mentioned previously, the impact of group residential care will likely differ with children's age, with young children being more vulnerable to negative outcomes.

Given this range of potentially very serious impacts, the question is to what extent they are inevitable and to what extent they are avoidable. The most obvious response relates to treatment of infected adults. It is quite possible that, with appropriate quality treatment, the majority of children with infected parents could reach adulthood before their parents die. Access to treatment in highly affected countries is improving. Some countries have reached high levels, but most highly affected regions are yet to reach 50% coverage (WHO, 2007). Moreover, access to appropriate second-line treatment is still problematic in many situations, limiting the increase in life expectancy.

A recent study found that adult treatment is associated with significant gains for children within the household (Thirumurthy, Zivin, & Goldstein, 2006). Educational indicators and health outcomes both appear to improve soon after the adult starts the programme. Treatment not only reduces household costs but also redistributes them away from the family and children and towards the service provider.

Aside from treatment, wealthy households with reserves of financial and human resources in contexts where services are available and accessible are not immune from being affected by HIV, but they are strong enough to protect their children from many of the impacts of adult infection. If it is possible for the actions of these households to protect children, then the impacts which children experience as a result of adult illness result from a failure to adequately strengthen poor families.

In terms of strengthening family financial resources, cash transfer interventions appear to provide a very promising means of support in this context (Adato & Bassett, 2008). While the evidence is not as strong, evaluations of support interventions suggest that they can also be provided to assist with shortfalls in human resources (Wakhweya & Dirks, 2008). Families can therefore be strengthened and, once

strengthened, they can increase the protection they offer children and thereby reduce the impacts children feel.

It is also important to ask to what extent the costs are inevitable once the death has been experienced. Those impacts that result from financial constraints are obviously avoidable. Those that result from there being fewer, or lower quality, human resources could, to some extent, be addressed by programmes that seek to support caregivers and so are avoidable. There is no shortage of labour in most high-prevalence contexts, so human resource constraints would mostly relate to accessing or skilling human resources. The impacts that result from new caregivers having lower levels of caring intentions towards children, or the changing power relationships leading to fewer resources being devoted to children, or if children have fewer opportunities to form secure bonds, are more difficult to classify. They could be considered avoidable in so far as interventions could reduce these family inactions. There is, however, limited evidence of the effectiveness of outside services in influencing such actions as discrimination, although there are some promising approaches. In terms of discrimination in allocations, arguably, if more resources were provided to households, even if children were discriminated against they would likely receive more than they would have if the additional resources were not provided.

## Conclusions

This paper has attempted to identify the pathways of impact of HIV/AIDS on children so as to be clear on all the possible points of intervention. It is apparent that the impacts felt by children are not simply unfortunate, inevitable consequences of this epidemic. A strong and supported family with good access to quality services can deflect almost all of the impact. What is more important is that, it suggests that the impacts on children associated with HIV/AIDS are to a larger extent a result of a failure to respond to poverty. It is against the backdrop of the weakened families that impacts find their way through to children.

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